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ABSTRACT

The booklet provides an overview of the federal and state programs which were established to coordinate and initiate services for persons with developmental disabilities. The scope of the Developmental Disabilities Assistance and Bill of Rights Act is explored and the definition of developmental disability explained. The role and functions of the state developmental disabilities program are covered in terms of state planning councils, state plans for services to persons with developmental disabilities, and information on state allotments. Discretionary special project grants to extend or improve services are discussed with a list of service-related activities that are eligible for such funds. Requirements for protection and advocacy systems are briefly considered. Congressional findings regarding the rights of persons with developmental disabilities are reviewed, followed by a summary of the university affiliated training programs designed to provide interdisciplinary training. A final section outlines authorizations and appropriations for developmental disabilities programs. (CL)

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THE DEVELOPMENTAL DISABILITIES PROGRAMS: STATUTORY AUTHORITY AND BUDGET INFORMATION

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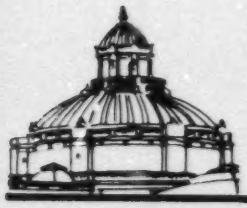

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ABSTRACT

The developmental disabilities programs were established to coordinate and initiate services for persons with developmental disabilities. The programs include State grants for planning and demonstration services, protection and advocacy systems, special projects, and interdisciplinary training for personnel serving the developmentally disabled.

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THE DEVELOPMENTAL DISABILITIES PROGRAMS: STATUTORY AUTHORITY AND BUDGET INFORMATION

INTRODUCTION

The Developmental Disabilities Assistance and Bill of Rights Act, 1/ which is authorized through FY 1984, establishes a mechanism for planning and coordinating services and protecting the rights of persons with developmental disabilities. Although the definition of the term developmental disability previously specified disabling conditions such as mental retardation and cerebral palsy, the definition is now based on a broad spectrum of functional limitations which are severe and chronic in nature. The Act presents the following congressional findings regarding persons with developmental disabilities: 2/

> (1) there are more than two million persons with developmental disabilities in the United States;
>
> (2) individuals with disabilities occurring during their developmental period are more vulnerable and less able to reach an independent level of existence than other handicapped individuals who generally have had a normal developmental period on which to draw during the rehabilitation process;
>
> (3) persons with developmental disabilities often require specialized lifelong services to be provided by many agencies in a coordinated manner in order to meet the persons' needs;
>
> (4) general service agencies and agencies providing specialized services to disabled persons tend to overlook or exclude persons with developmental disabilities in their planning and delivery of services; and

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1/ This Act may be cited as the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, as amended by Public Laws 90-170, 91-517, 94-103, and 95-602. All sections referenced in footnotes in this paper are part of this Act unless otherwise identified.

2/ Section 101(a).

(5) it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care, to meet the needs of persons with developmental disabilities.

State level planning councils receive Federal funds for purposes of planning, evaluating, and coordinating existing services and establishing and funding services in areas of priority need. The protection and advocacy of rights are also major State functions. A State plan approved by the Secretary of Health and Human Services is required for receipt of Federal funds. The State planning council is appointed by the Governor of each State and must include representatives of the principal governmental agencies and other groups concerned with services to the developmentally disabled. At least one-half of the members of the State planning council must be persons with developmental disabilities or immediate relatives or guardians of such persons.

Responsibilities at the national level focus primarily on improving the effectiveness of the State planning councils, administering special demonstration projects and university training programs, and providing technical assistance.

For fiscal year 1983, a continuing appropriation provides $60.5 million to carry out the various programs authorized under the Act.

The developmental disabilities program is administered by the Administration on Developmental Disabilities, Office of Human Development Services, Department of Health and Human Services.

I. THE DEFINITION OF DEVELOPMENTAL DISABILITY

Prior to the 1978 amendments to the Act, the term developmental disability was defined to include mental retardation, cerebral palsy, epilepsy, and autism. A major provision of the 1978 amendments expanded this definition by deleting all references to specific handicapping conditions and establishing a definition based on functional limitation: 3/

> The term "developmental disability" means a severe, chronic disability of a person which--
>
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> (B) is manifested before the person attains age twenty-two;
>
> (C) is likely to continue indefinitely;
>
> (D) results in substantial functional limitations in three or more of the following areas of major life activity; (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility; (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and
>
> (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

The primary considerations in determining whether a person has a developmental disability include the severity and the chronic nature of the disability, the manifestation of the disability prior to age twenty-two, and the degree of limitation the disability causes in the activities of daily life. Whereas a medical diagnosis may have previously established a handicapping condition as a developmental disability, it is now necessary to evaluate the individual in terms of

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3/ Section 102(7).

his or her ability to perform the major life activities which are necessary for self-sufficiency in society. A developmentally disabled person is one who is substantially limited in three or more major life activities. These major activities include the ability to care for one's daily personal needs, the ability to understand and express language, the capacity to learn appropriate to one's age group, the ability to move about without assistance or support, the discipline and understanding necessary to direct one's life, and the capacity for independent living and economic self sufficiency. The population eligible under this Act is composed of those individuals substantially disabled early in life who are in need of lifelong services which are individually planned and coordinated.

II. STATE DEVELOPMENTAL DISABILITIES PROGRAMS

A. State Planning Councils

Each State which receives a Federal allotment under the Act is required to have a State planning council to serve as an advocate for persons with developmental disabilities. Members of the council are appointed by the Governor and must include representatives of the principal State agencies, training facilities and local public and private agencies which serve persons with developmental disabilities. At least one-half of the membership of each council must consist of persons who are immediate relatives or guardians of persons with mentally impairing developmental disabilities. The half of the council membership comprised of disability-related individuals is to have the following composition:

- at least one-third must be persons with developmental disabilities, and
- at least one-third must be immediate relatives or guardians of mentally impaired individuals and at least one such member must be an immediate relative or guardian of an institutionalized person with a developmental disability.

The State plan is developed jointed by the State planning council and the the State agency administering the developmental disabilities program. The State plan must specify the areas of priority service to be addressed. The council is responsible for monitoring and evaluating the State plan and for reviewing, to the extent feasible, all State plans affecting persons with developmental disabilities. These other State plans could include maternal and child health services, special education, vocational rehabilitation, and social services.

B. State Plans for Services to Persons with Developmental Disabilities

The State plan sets forth major unmet service needs of persons with developmental disabilities and identifies services to be provided. The plan also designates the State agencies responsible for providing the services under the State plan. The fundamental purpose of the plan is to set forth the specific objectives to be achieved and to identify the programs and resources to be used to meet these objectives. The resources identified in the plan include both the use of the State allotment provided under the developmental disabilities program 4/ and the services provided under other State-Federal programs. Other State-Federal programs include education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, and mental health.

The Act authorizes the expenditure of funds on services for persons with developmental disabilities. The services provided are required to focus primarily on the specified priority service areas discussed below, but may also include a broad array of specialized services or adaptations of generic services such as: diagnosis, evaluation, treatment, personal care, day care, special living arrangements, training, education, sheltered employment, recreation, counseling, protective services, information and referral services, and transportation services.

Prior to the 1978 amendments to the developmental disabilities program, States were free to choose the areas of priority need on which use the Federal allotment. However, the 1978 amendments to the Act require that States choose

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4/ Authorized under section 131.

among four different areas of priority services for the expenditure of most of the Federal funds. The four priority services areas are:

- case management services to aid in obtaining the range of help needed;
- child development services to assist young children to overcome the handicapping effects of developmental disabilities;
- alternative community living arrangement services to help maintain residential options; and
- nonvocational social-developmental services to provide suitable daytime activities.

The Act describes the four priority services as follows: 5/

> (C) The term "case management services" means such services to persons with developmental disabilities as will assist them in gaining access to needed social, medical, education, and other services; and such term includes--
>
> (i) follow-along services which ensure, through a continuing relationship, lifelong if necessary, between an agency or provider and a person with a developmental disability and the person's immediate relatives or guardians, that the changing needs of the person and the family are recognized and appropriately met; and
>
> (ii) coordination services which provide to persons with developmental disabilities support, access to (and coordination of) other services, information on programs and services, and monitoring of the persons' progress.
>
> (D) The term "child development services" means such services as will assist in the prevention, identification, and alleviation of developmental disabilities in children, and includes (i) early intervention services, (ii) counseling and training of parents, (iii) early identification of developmental disabilities, and (iv) diagnosis and evaluation of such development disabilities.
>
> (E) The term "alternative community living arrangement services" means such services as will assist persons with developmental disabilities in maintaining suitable residential arrangements in the community, and includes in-house services (such as personal aides and attendants and other domestic assistance and supportive services), family support services, foster care services, group living services, respite care, and staff training, placement, and maintenance services.
>
> (F) The term "nonvocational social-development services" means such services as will assist persons with developmental disabilities in performing daily living and work activities.

5/ Section 102(8).

The Act requires that currently no more than two of the priority services areas may be specified in the State plan for substantial funding. 6/

The State plans for developmental disabilities also must provide certain assurances such as the following:

- Services provided must meet standards prescribed in regulation.
- Buildings used in connection with the delivery of services must meet the specifications of the Architectural Barriers Act of 1968.
- Services are to be provided in an individualized manner and an individualized habilitation plan is to be developed for each person receiving services under the plan.
- The human rights of all persons with developmental disabilities (especially persons without familial protection) who are served under the Act are to be protected according to the rights specified in the Act, discussed below.
- The plan must provide for an assessment of the adequacy of the skill level of and training for professionals and paraprofessionals serving the developmentally disabled.
- Volunteers are to be used to the maximum extent feasible for the delivery of services to the developmentally disabled, including volunteers serving under the Domestic Volunteer Service Act of 1973.

C. State Allotments

The State grants for planning and provision of services for persons with developmental disabilities are allotted on the basis of State population,

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6/ Section 133(b)(4) requires that the number of priority service areas addressed in the plan is to be restricted according to the total amount of funds appropriated for any given fiscal year. The State plan must provide that not less that $100,000 or 65 percent of the amount available to the State, whichever is greater, must be expended in the priority service areas. If the total appropriation for State grants is under $60 million, the amount stated above must be expended in no more than two priority service areas. If the total appropriation is between $60 million and $90 million, the amount above must be expended on no more than three priority service areas.

extent of need for services for persons with developmental disabilities, 7/ and the financial need of the respective States. 8/ Matching funds are required on a 75 percent Federal-25 percent State basis, except in areas of urban or rural poverty where the match is 90 percent Federal-10 percent State. 9/ The minimum allotment to States is $250,000 or the amount received in fiscal year 1978, whichever is greater. The minimum amount for the territories is $100,000. 10/

7/ As determined by the number of persons in the State receiving benefits under the Social Security Adult Disabled Child Program (Section 202(d)(1)(B)(ii) of the Social Security Act.

8/ Specified in section 132(a)(1). A three-year per capita income average is used to reflect financial need.

9/ Specified in section 103.

10/ Specified in section 132(a)(2). The territories include: American Samoa, Guam, Virgin Islands, Northern Mariana Islands, and the Trust Territory of the Pacific Islands.

III. SPECIAL PROJECT GRANTS

Discretionary special project grants to expand or improve services provide funding for service demonstrations, technical assistance, and training. Protection and advocacy demonstration projects are also emphasized. Special project grants are administered at the Federal level. Only public or private nonprofit agencies are eligible to receive these grants. Special project funds are to be used only for projects conducted in more than one State, projects involving two or more Federal agencies, or projects which are otherwise of national significance. The following service-related activities are eligible for special project funds: 11/

> (1) public awareness and public education programs to assist in the elimination of social, attitudinal, and environmental barriers confronted by persons with developmental disabilities;
> (2) coordinating and using all available community resources in meeting the needs of persons with developmental disabilities (especially those from disadvantaged backgrounds);
> (3) demonstrations of the provision of services to persons with developmental disabilities who are also disadvantaged because of their economic status;
> (4) technical assistance relating to services and facilities for persons with developmental disabilities, including assistance in State and local planning or administration respecting such services and facilities;
> (5) training of specialized personnel needed for the provision of services for persons with developmental disabilities or for research directly related to such training;
> (6) developing or demonstrating new or improved techniques for the provision of services to persons with developmental disabilities (including model integrated service projects);
> (7) gathering and disseminating information relating to developmental disabilities;

11/ Section 145(b).

(8) improving the quality of services provided in and the administration of programs for such persons; and

(9) developing or demonstrating innovative methods to attract and retain professionals to serve in rural areas in the habilitation of persons with developmental disabilities.

IV. PROTECTION AND ADVOCACY SYSTEMS

To assure that the constitutional and other rights of developmentally disabled persons are safeguarded, the Act requires that States have in effect a system to protect and advocate these rights. 12/ The system must have the authority to pursue legal and administrative remedies to assure protection of rights. Remedies include negotiations with agencies administering service programs as well as litigation. The protection and advocacy system must be independent of any agency providing services to persons with developmental disabilities and may not be administered by the State planning council. The Act authorizes specific funding for the protection and advocacy systems. These funds are allotted on the same basis as the State grants except that no matching funds are required. The minimum grant to a State for a protection and advocacy system is $50,000 or the amount received the previous fiscal year, whichever is greater.

12/ Required under section 113.

V. RIGHTS OF THE DEVELOPMENTALLY DISABLED (CONGRESSIONAL FINDINGS)

Congress has established findings regarding the rights of persons with developmental disabilities. These findings, which are not legally binding, provide guidance for the service system and are in addition to any constitutional or other rights afforded to all persons. The dependent nature of many developmentally disabled persons puts them at risk of inhumane treatment by caretakers and others who provide the services essential to survival. Many of the rights are focused on conditions in institutions where some of the more severely disabled individuals reside. The following findings are presented under section 111:

> (1) Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities.
>
> (2) The treatment, services, and habilitation for a persons with developmentally disabilities should be designed to maximize the developmental potential of the persons and should be provided in the setting that is least restrictive of the person's personal liberty.
>
> (3) The Federal Government and the States both have an obligation to assure that public funds are not provided to any institutional or other residential program for persons with developmental disabilities that--
>
> > (A) does not provide treatment, services, and habilitation which is appropriate to the needs of such persons; or
> >
> > (B) does not meet the following minimum standards;
> >
> > > (i) Provision of a nourishing, well-balanced daily diet to the persons with developmental disabilities being served by the program.
> > >
> > > (ii) Provision to such persons of appropriate and sufficient medical and dental services.
> > >
> > > (iii) Prohibition of the use of physical restraint on such persons unless absolutely necessary and prohibition of the use of such restraint as a punishment or as a substitute for a habilitation program.

(iv) Prohibition on the excessive use of chemical restraints on such persons and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such persons.

(v) Permission for close relatives of such persons to visit them at reasonable hours without prior notice.

(vi) Compliance with adequate fire and safety standards as may be promulgated by the Secretary.

(4) All programs for persons with developmental disabilities should meet standards which are designed to assure the most favorable possible outcome for those served, and--

(A) in the case of residential programs serving persons in need of comprehensive health-related, habilitative, or rehabilitative services, which are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on January 17, 1974 (39 Fed. Reg. pt. II), as appropriate when taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

(B) in the case of other residential programs for persons with developmental disabilities, which assure that care is appropriate to the needs of the persons being served by such programs, assure that the persons admitted to facilities of such programs are persons and assure that the facilities under such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and

(C) in the case of nonresidential programs, which assure the care provided by such programs is appropriate to the persons served by the programs.

VI. UNIVERSITY AFFILIATED FACILITIES

University affiliated training programs provide interdisciplinary training for persons preparing to serve the developmentally disabled. 13/ These programs, which are affiliated with colleges or universities, also include demonstration service programs for the developmentally disabled. The programs provide innovative, exemplary services and disseminate the findings of such services to other agencies assisting the developmentally disabled. The Act also provides for the establishment of satellite centers to serve areas not served by a university affiliated facility. Other activities of these facilities include the assessment of need for trained personnel to serve the developmentally disabled and the provision of service-related training to practitioners providing service. University affiliated facilities also conduct research to help produce more efficient and effective methods for delivering services and for training the professionals, paraprofessionals, and parents who provide these services. Grants for this program are administered at the Federal level. Matching funds are required on a 75 percent Federal-25 percent State basis except in poverty areas. The amount of any grant to a university affiliated facility in any fiscal year may not be less than $150,000.

13/ Authorized under section 121.

VII. FUNDING FOR THE DEVELOPMENTAL DISABILITIES PROGRAM

The Omnibuis Budget Reconciliation Act of 1981, P.L. 97-35, reauthorized the developmental disabilities programs for fiscal years 1982, 1983, and 1984 at $61.18 million each year. The continuing appropriation for fiscal year 1983, P.L. 97-377, funds the programs at $60.5 million. Because the appropriation level for fiscal year 1983 is nearly equal to the authorization level for fiscal year 1984, the Senate Committee on Labor and Human Resources has proposed to increase the authorization level for fiscal year 1984 to allow for possible program expansion. Title II of S. 1340, reported from the Committee on May 18, 1983, would raise the total authorization level 4.9 percent to $64.2 million for fiscal year 1984.

The Administration budget request for fiscal year 1984 is $41.298 million, 32 percent less than the fiscal year 1983 appropriation.

Table I shows authorizations and appropriations for the four developmental disabilities programs.

TABLE I. Authorizations and Appropriations for the Developmental Disabilities Programs (in millions)

	Authorizations		Appropriations		
	FY 1982-84 P.L. 97-35	FY 1984 S. 1340	FY 1982	FY 1983 Continuing Appropriation	FY 1984 Administration Request
Grants to States (Sec. 131)	$43.18	$45.4	$41.453	$43.18	$24.674
Protection and Advocacy (Sec. 113)	8.00	8.4	7.680	7.32	7.303
Special Project Grants (Sec. 145)	2.50	2.6	2.350	2.50	2.294
University Affiliated Facilities (Sec. 123)	7.50	7.8	7.200	7.50	7.027
TOTAL	$61.18	$64.2	$58.683	$60.50	$41.298